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Considerations Before Establishing an Environmental Health Registry

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Abstract

Public health registries can provide valuable information when health consequences of environmental exposures are uncertain or will likely take long to develop. They can also aid research on diseases that may have environmental causes that are not completely well defined.

We discuss factors to consider when deciding whether to create an environmental health registry. Those factors include public health significance, purpose and outcomes, duration and scope of data collection and availability of alternative data sources, timeliness, availability of funding and administrative capabilities, and whether the establishment of a registry can adequately address specific health concerns.

We also discuss difficulties, limitations, and benefits of exposure and disease registries, based on the experience of the Agency for Toxic Substances and Disease Registry.

The use of public health registries has become increasingly common in the past 2 decades. Although they are widespread in the context of immunizations, cancer epidemiology, and drug development research, the field of environmental health has also benefited from the establishment of a number of disease and exposure registries.

A registry is generally defined as a set of records containing systematically collected, standardized data about individual people. These data are typically acquired, maintained, and updated over a prolonged period, usually years. Registries range from only a listing of exposed individuals with associated contact information to a research repository of

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Contributors

V. C. Antao led the conceptualization, writing, and revisions of the article. O. I. Muravov wrote the first draft of the article and contributed to subsequent revisions. J. Sapp II, T. C. Larson, L. L. Pallos, M. E. Sanchez, G. D. Williamson, and D. K. Horton contributed to the development and all revisions of the article.

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information that includes demographics, exposure data, and health information. A public health registry is set up to accomplish a public health goal or activity. It might be used to obtain information on people who have a particular disease, a condition or a risk factor that predisposes them to illness from a health-related event, or previous exposure to substances or circumstances known or suspected to cause adverse health effects. The particular data assembled are a function of the purpose of the registry. The variables might be chosen to help study or detect specific health problems or to study treatments in specific individuals or disorders. In the context of environmental health, registries include information regarding individual exposures to chemical or physical environmental agents or the known or potential consequences of such exposures.

The central purpose of a registry is to facilitate epidemiological research or provide information to registrants about a certain disease, exposure, or event. Registries are also used to generate relevant statistics about the group of registered people. We discuss the main factors to consider when deciding whether to create an environmental health registry. We also discuss some of the difficulties, limitations, and benefits of registries, based on the experience of their use by the Agency for Toxic Substances and Disease Registry (ATSDR) in the United States.

WHY CONSIDER CREATING A REGISTRY

Registries are an important public health tool. They can help communities learn more about a certain disease, exposure, or event. However, whether or when registries should be established when a particular concern is raised is not always clear. In general, the reasons to consider creating an environmental health registry fall into 2 broad categories: (1) confirmed exposure, but the consequences are unclear or unknown, and (2) confirmed disease and environmental etiology is plausible or possible. Other considerations regarding the need for a registry include the potential for harm from exposure, the potential benefits of a registry, and public concerns.

Confirmed Exposure, but Consequences Unclear

A registry might be justified when it is unclear whether people who share a common exposure to a chemical, physical, or radioactive agent will develop an illness as a result of that exposure or when some aspect of the risk is not well understood, such as the latency period after exposure. Another unknown might be whether a disease caused by a particular exposure has the same clinical course or outcome as when it arises under other, previously studied circumstances. Because an exposure might affect children differently than adults or elderly people more than younger people, the age range of the exposed group might influence the decision of whether to create a registry. Indeed, any point of substantial uncertainty about the final consequences of the exposure may be a reason to use registry techniques to study an exposure. An exposure registry may also provide the opportunity for longitudinal, repeated-measures evaluation of effect biomarkers such as neurobehavioral, immunologic, and pulmonary function tests.

Confirmed Disease, Possible Environmental Etiology

Some scientists investigating the pathogenesis of certain diseases of unknown etiology suspect the cause or contributing cause to be environmental exposure. Examples of such diseases include multiple sclerosis, amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease), scleroderma, systemic lupus erythematosus, and polycythemia vera.⁷ For diseases with suspected environmental causes, the patterns of time, place, and people generated from a registry may provide important insights into the etiology of a disease, including the potential importance of environmental antecedents.

Potential for Harm From Exposure

Although virtually everyone experiences many exposures from the physical and chemical environment, most do not warrant the expensive and resource-intensive effort required for a registry. For a registry to be justified, the exposure must present a clear element of risk. In general, an epidemiological study or approach other than a registry would be more appropriate if the risk posed by a situation encountered in the environment is clearly within tolerable limits.

Potential Benefit From a Registry

An obvious requirement for a registry is that it benefits researchers and the participants. The precise benefits to be derived from a registry in a given situation must be carefully considered. A registry might, for example, provide data that help in developing treatment of a condition or provide new scientific knowledge that may help others with similar conditions. Registrants may directly benefit if consequences of exposure or environmentally induced disease are discovered more rapidly as a result of the registry-based investigation. Such early knowledge of consequences potentially allows screening of registrants. Early detection through screening might then enable a registrant to seek specific treatment at a relatively early stage, when the treatment might be most effective. For example, after the promulgation of the Patient Protection and Affordable Care Act in 2010, people exposed to asbestos in the town of Libby, Montana, became entitled to receive Medicare benefits regardless of age if diagnosed with an asbestos-related health condition. Most of these people are enrolled in ATSDR's Tremolite Asbestos Registry (TAR), which facilitates contact with health care providers (http://www.atsdr.cdc.gov/Asbestos/sites/libby_montana).

Registrants may benefit directly if the registry permits studies that reveal the etiology or pathophysiology of a health problem that they are known to have or if the registry facilitates clinical trials of a potential treatment. Even the communication with registrants afforded by the registry infrastructure can yield benefits, if it is used to transmit useful information. Such information may include updates on new scientific and medical developments relevant to the registrants. These may have been discovered or developed from registry-based studies or completely independently of the registry and the registrants. Registrants might also be invited to participate in research studies and clinical trials. If no personal direct benefit for registrants exists, other than helping others as a result of enrolling, this needs to be made clear to them.

Finally, clear communication with participants and researchers must be established. Results may be disseminated through community reports, scientific articles, and even data query systems, such as the one created for the World Trade Center (WTC) Health Registry (<https://a816-healthpsi.nyc.gov/epiquery/WTC/index.html>).

Public Concern

Complaints about the potential health consequences of environmental exposures from community members who feel their concerns are being neglected must be dealt with in an objective manner consistent with established best practices in the field of environmental public health.

Nevertheless, a dispassionate, objective, and reasonably extensive review of health concerns sometimes yields no biologically plausible basis for a concern that has been raised. In the case of potential cancer clusters, for example, investigations rarely demonstrate a clear association with an environmental contaminant. Sometimes these investigations can also have unintended consequences. They might increase the existing fear and uncertainty in the community brought on by the perception, for example, that a suspected cancer cluster exists, which might have a negative social and economic impact. Even a scientifically valid and objective review may not be accepted if members of the community do not trust those seeking to address their concerns. To avoid mistrust or disagreements, all investigations must be conducted transparently, preferably with close consultation among all parties.

A registry is not indicated if the exposure or illness does not require at least several years, if not decades, of data collection. Although there are exceptions, communities are more typically concerned with current exposure or current illness. If an objective analysis reveals no cause for concern, the funds, time, and organizational effort required to establish a registry may be misspent.

WHAT TO CONSIDER BEFORE ESTABLISHING A REGISTRY

Before moving forward with the procedures to establish a registry, 2 broad issues must be considered: acceptability and feasibility of a registry (see the box on page e3). Factors related to the acceptability of or justifications for creating a registry are as follows.

Public Health and Scientific Significance

Sometimes, the very nature of an event may warrant strong consideration of whether to create a registry, such as mass casualty events or unique events in which there is a potential to learn from the event and improve emergency preparedness and response. Such events may include the natural or anthropogenic spread of toxic, infectious, or otherwise hazardous materials that have contaminated, or have the potential to contaminate, a large population or geographical area; an especially vulnerable affected population (e.g., children, elderly people, minorities); or an event that consists of exposure to a highly toxic agent.

A registry can be justified if it has the potential to make an important contribution to the literature on etiology of a disease or effects of an exposure; promotes new methods, such as new biomarkers or the enhancement of existing biomarkers or exposure modeling methods;

evaluates a population that has not been studied sufficiently in the past; or facilitates the evaluation of an effect of exposure during a particular period, such as in utero, during infancy, or later in life, that could use additional study.

Registry Purpose and Outcomes

The main reasons to start a registry are to determine the potential health consequences of an exposure. Most registries need to have at least 1 of the following outcomes:

- creation of a means for reducing morbidity or mortality,
- improvement in the delivery of health services,
- provision of information for policy or administrative decisions,
- provision of a justification for an intervention (e.g., closing a contaminated well), and
- generation of data for research.

The purpose will drive the specific variables to be collected.

Duration and Scope of Data Collection

Usually, registries are justified for data collection over a long period and for the entire target population. Because registries are a very expensive method of obtaining information, it is important to determine whether the data being sought have already been collected elsewhere and whether a registry is the most appropriate means for addressing specific questions. In certain instances, a focused health study can often collect the necessary information at a substantially lower cost and provide information more quickly to affect a more timely public health response. Several factors are related to the feasibility of creating a registry.

Concerns of the Affected Population and Timeliness

A registry has the potential to address a key health or exposure concern of an affected population. This is possible if the sample size is sufficient, adequate data on exposures are available, and registrants have no serious confounding exposures. In addition, developing a participatory mechanism (e.g., a community action panel) is feasible so that the affected population can have input into the registry's design and the research questions.

Sometimes, the time between the exposure of interest and the actual start of data collection may be too long to allow adequate recruitment or accurate reporting. For US agencies, additional time is needed to obtain approvals for data collection under the Paperwork Reduction Act and from institutional review boards. Emergency procedures exist to expedite approvals, but the procedures might still hinder the collection of data during acute releases of short-acting agents. Other important aspects are the time allotted for data collection and how long it will take for results to be reported.

Funding and Scientific and Administrative Resources

Sufficient funding, staffing, communication, and other administrative capabilities are important factors to evaluate before initiating a registry. First and foremost, funding must be

available for the initial operation and the long-term maintenance of the registry. Implementation costs are usually in the millions of dollars and, depending on the duration of the registry, long-term maintenance can also be very expensive. Implementation costs for several ATSDR registries are presented in Table 1. In the United States, funding for environmental health emergencies can be sought from the Federal Emergency Management Agency, state emergency response agencies, and similar entities. In certain situations, funding may be available from the Environmental Protection Agency, the National Institutes of Health, or the National Institute for Environmental Health Sciences. For certain diseases, approaching the disease-specific professional organization or advocacy group (e.g., American Heart Association, Amyotrophic Lateral Sclerosis Association) could be considered. Should there be sufficient congressional interest, support might be available from members of Congress.

Sufficient staffing to complete data collection, entry, and analysis is vital. Required staff may include medical staff, epidemiologists, environmental health scientists, toxicologists, sociologists, data managers, statisticians and data analysts, information technology specialists, computer scientists, attorneys, ethicists, budget and personnel analysts, and project managers. Appropriate communication capabilities are required to inform eligible individuals about establishing a registry and to disseminate registry data, findings, and educational materials among relevant groups. The sustainability of the registry must also be considered, and appropriate financial, administrative, and human resources guaranteed over its existence.

TYPES OF REGISTRIES

If it is decided that a registry is warranted, the type of registry to establish must be determined. Environmental health registries consist of 2 fundamental types.

Exposure Registries

An exposure registry follows a group of people who have some specific exposure that may lead to development of a disease or condition. The ongoing study of atomic bomb survivors from the cities of Hiroshima and Nagasaki, Japan, carried out since 1955 by the Radiation Effects Research Foundation and its predecessor organization, the Atomic Bomb Casualty Commission, can be considered an exposure registry. Studies arising from this organized follow-up of people who survived a brief but intense dose of ionizing radiation have led to important advances in our understanding of human responses to this unusual environmental circumstance.

Disease Registries

Disease registries involve follow-up of people diagnosed as having a specific disease or health condition. Disease registries are diverse in their purposes. If the cause of a disease is not well understood, the registry-based accumulation of information about a substantial number of cases may yield clues about its etiology or pathogenesis, particularly if the disease or condition is rarely encountered in the experience of individual practitioners. Many

genetic diseases, for example, are relatively rare and can be more fully studied with the aid of the systematic effort to acquire case data that is typically part of registry operations.

Disease registries can help in elucidating the long-term consequences of an epidemic or disease occurring in the context of unique environmental circumstances. The 20 000 victims of the toxic oil syndrome epidemic that occurred in Spain in 1981 have been followed as a cohort for more than 2 decades, yielding important information regarding the ultimate consequences of this unique illness among affected people.

Registries of common diseases (e.g., cancer, stroke, myocardial infarction) are also useful. Many studies of environmental exposures have relied on information from state cancer and birth defect registries. Efforts in the United States and abroad to establish registries for autism spectrum disorders, attention deficit hyperactivity disorder, and other population-based diseases will also facilitate such research. Disease registries can be used to collect data to assess patterns of disease, the impact of diagnostic tests on medical decision-making, the effects of different treatments on patient outcome, and the quality of care rendered at specific health care institutions. Similarly, trauma registries follow outcomes of specific types of injuries at different institutions and may also assist in assessing the quality of care being rendered.

EXAMPLES OF ENVIRONMENTAL HEALTH REGISTRIES

Since its creation in 1980, ATSDR, under the US Department of Health and Human Services, has been involved in developing and maintaining a series of exposure and disease registries (Tables 1 and 2).

National Exposure Registry

The National Exposure Registry (NER) collected data on people exposed to benzene, trichloroethylene, dioxin, and 1,1,1-trichloroethane at various sites in the United States. Enrollees were from residential sites in 7 states: Indiana, Illinois, Michigan, Missouri, New York, Pennsylvania, and Texas. NER was created by ATSDR in 1989 and collected data until 2000. The primary goal of NER was to fill data gaps regarding long-term health effects related to exposures to hazardous substances and their mixtures, particularly in drinking water. Data were collected using face-to-face interviews with people on site or living near specified areas; potentially eligible people living outside the area were interviewed by telephone. Annual and biennial updates were carried out by computer-assisted telephone interviewing. Questionnaires were used to collect basic demographic, environmental, occupancy, occupational, health, and reproductive data, along with the names of 3 contact people.

In addition, a list of the chemicals to which registrants were exposed was collected. When compared with national estimates, NER data for people exposed to the hazardous substances demonstrated that 5 health conditions were reported in excess: anemia and other blood disorders; all cancers; skin rashes, eczema, or other skin allergies; urinary tract disorders, including prostate trouble; and stroke. The lack of adequate individual exposure measures was the most limiting factor in the NER design. Nevertheless, the NER is one of the most

comprehensive data repositories tracking specific environmental chemical exposures and registrants' health conditions over time.

Tremolite Asbestos Registry

The TAR is a registry of people exposed to elongated mineral particles identified as a mixture of asbestiform amphiboles, including winchite, richterite, and tremolite asbestos, in Libby, Montana. Enrollees were categorized as workers, household contacts of workers, and other Libby residents. The TAR was developed and has been maintained by ATSDR since 2003. The registry is used to communicate with registrants about medical benefits and participation in health studies. Data from the registry are used to assess the health effects of exposure to Libby amphiboles. To reduce costs, participants in community-based health screening offered by ATSDR were invited to simultaneously enroll in the registry. Information collected for the TAR includes contact, demographic, exposure, and health outcomes, including spirometry data and interpretations of chest radiographs. Although some industrial hygiene measurements were available for some Libby residents with occupational exposure, exposures for most registrants had to be characterized using self-reports of exposure pathways.

TAR data revealed that exposure to Libby amphibole is associated with nonmalignant and malignant asbestos-related diseases and that a strong exposure-response relationship exists for many of these health outcomes. Limitations of the TAR include potential self-selection bias and the lack of individual exposure measures for most participants, especially household contacts and other Libby residents. A strength of the TAR is that it includes a large proportion of the potentially affected population of this relatively small and isolated community. Furthermore, the TAR may allow evaluation of long-term health trends of residents in relation to clean-up being conducted by the Environmental Protection Agency.

World Trade Center Health Registry

The WTC Health Registry includes people who were most directly exposed to the environmental effects from the destruction of the WTC towers in New York City on September 11, 2001 (9/11). Major enrollment groups include rescue and recovery workers, lower Manhattan residents, lower Manhattan office workers, passersby, and students and staff in lower Manhattan schools. The WTC Health Registry was implemented in 2003 by ATSDR and the New York City Department of Health and Mental Hygiene. It is currently administrated by the New York City Department of Health and Mental Hygiene and sponsored by the National Institute for Occupational Safety and Health. The goals of the WTC Health Registry are to identify and track long-term physical and mental health effects of the 9/11 WTC attack, disseminate findings and recommendations, and develop and disseminate disaster preparedness and public policy information for use in the event of future disasters.

Data have been gathered through periodic surveys using computer-assisted telephone interviewing, computer-assisted in-person personal interviewing, or Web-based interviewing. Enrollees were asked about physical health outcomes, including injuries, new or worsening respiratory and nonrespiratory symptoms, and specific conditions diagnosed

by a physician or other health professional after 9/11. Mental health outcomes included probable posttraumatic stress disorder and serious psychological distress in the 30 days before the interview. Exposure questions varied according to enrollment group. Rescue and recovery workers, for example, were asked about their use of respiratory protective equipment, whereas residents of lower Manhattan were asked about damage to their homes and presence of dust.

Major accomplishments of the WTC Health Registry include increased reporting of newly diagnosed respiratory symptoms, asthma, posttraumatic stress disorder, and serious psychological distress. A significant finding was that rescue and recovery workers who wore respirators on 9/11 were less likely to report respiratory problems 5 to 6 years after 9/11 than those who went without adequate respiratory protection. The most important limitations of the WTC Health Registry are selection bias and recall bias. The WTC Health Registry is the largest registry to track the health effects of a disaster in the United States. It provides a unique perspective on the health effects of the 9/11 WTC disaster and is an invaluable resource to inform health care services, project needs for affected populations, and link affected individuals to services.

National Amyotrophic Lateral Sclerosis Registry

The National ALS Registry is a congressionally mandated program to collect and analyze data about people living with ALS in the United States. The ALS Registry was launched and has been maintained by ATSDR since 2010. The purposes of the registry are to quantify the incidence and prevalence of ALS in the United States, describe the demographics of people with ALS, and examine risk factors for the disease. It includes data from existing national databases, including Medicare, Medicaid, the Veterans Health Administration, and the Veterans Benefit Administration. It also includes information provided by people with ALS who answered a series of short surveys posted on a secure Web portal. These surveys gathered information about sociodemographic characteristics, occupational history, military history, cigarette smoking, alcohol consumption, physical activity, family history of neurodegenerative diseases, disease progression, residential history, pesticide exposures, occupations and hobbies involving toxic exposures, trauma (e.g., traumatic brain injury, electrical shocks), caffeine consumption, reproductive history, and health insurance information.

The National ALS Registry is the first national surveillance system to use existing administrative data as a major source of case ascertainment, and it is the only effort to gather nationwide data on ALS in the country. A recently published analysis of registry data found the prevalence of ALS in the United States to be 3.9 cases per 100 000 people. Limitations of the National ALS Registry include the possibility of underascertainment and the inability to calculate ALS incidence (because the date of onset is missing for most cases).

Other Environmental Health Registries

The US Department of Veterans Affairs maintains several registries to evaluate possible long-term health problems that might be related to exposure to specific environmental hazards during military service (<http://www.publichealth.va.gov/PUBLICHEALTH/>

[exposures/index.asp](#)). These registries include the Ionizing Radiation Registry, Agent Orange Registry, Gulf War Registry, Depleted Uranium Follow-Up Program, and Toxic Embedded Fragments Registry.

Several disasters and incidents have prompted the creation of other registries, both in the United States and abroad. Some examples include

- the registry of Hiroshima and Nagasaki atomic bomb survivors;
- the Three Mile Island Population Registry, established after a nuclear reactor leak;
- the Oklahoma City Bombing Registry, developed to follow people who were directly exposed to the bombing of the Alfred P. Murrah Federal Building;
- the Chernobyl Registries of Belarus, Russia, and Ukraine, after the 1986 nuclear accident;
- the Enschede Firework Disaster Health Surveillance Project, prompted by the explosion of a fireworks depot in the Netherlands; and
- the accidental polybrominated biphenyl contamination of livestock feed in Michigan in 1973.

More recently, an earthquake and tsunami caused extensive damage to the Fukushima Daiichi Nuclear Power Station in Japan. This prompted the US Department of Defense to create the Operation Tomodachi Registry (<https://registry.csd.disa.mil/registryWeb/Registry/OperationTomodachi/DisplayAbout.do>), which includes more than 75 000 people affiliated with the department who were on or near the mainland of Japan in the aftermath of that disaster.

Table 2 provides examples of how the criteria outlined here have been applied to actual situations for which creation of a registry was considered.

CONCLUSIONS

Registries are a powerful tool for environmental health data collection and follow-up. They may provide valuable information when the health consequences of certain environmental exposures are uncertain or will likely take a long time to develop. In addition, certain diseases may have environmental causes that are not completely well defined, and long-term data collection via a registry could provide important insights.

The various considerations that must be weighed when deciding whether to establish a registry do not constitute rigid criteria; rather, these factors should be evaluated within each individual context and adapted appropriately.

The significant costs of implementing and maintaining a registry warrant careful consideration. Before starting a registry, one must decide whether those costs are acceptable and whether funding will be available. Important criteria to consider in the decision process are the

- public health significance of the event,
- registry purpose and expected outcomes,
- duration and scope of data collection,
- existence of other data sources,
- timeliness of creation, and
- availability of funds and scientific and administrative capacity and expertise.

These factors should be taken in context and adapted to each situation.

Other issues to consider when making this decision include logistical difficulties when dealing with disaster situations, political issues related to community demands, and sensitivities when dealing with special populations. Various details must also be addressed after deciding to implement a registry, including data oversight, confidentiality, and security. Scientific and administrative concerns might include institutional review board and Office of Management and Budget approvals, establishment of an advisory board, and data release procedures and products. Practical aspects to address might include creation of data collection instruments, whether to collect data electronically or on paper forms, and outreach and communications strategies. Finally, although most legal concerns in the United States are state specific, data ownership and access may be an issue when registries are developed by federal agencies in collaboration with other institutions at the state or local level.

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References

1. Goldberg J, Gelfand HM, Levy PS. Registry evaluation methods: a review and case study. *Epidemiol Rev.* 1980; 2:210–220. [PubMed: 7000537]
2. Solomon DJ, Henry RC, Hogan JG, Van Amburg GH, Taylor J. Evaluation and implementation of public health registries. *Public Health Rep.* 1991; 106(2):142–150. [PubMed: 1902306]
3. Richesson R, Vehik K. Patient registries: utility, validity and inference. *Adv Exp Med Biol.* 2010; 686:87–104. [PubMed: 20824441]
4. Brooke, EM. *The Current and Future Use of Registers in Health Information Systems.* Geneva, Switzerland: World Health Organization; 1974. Publication No. 8
5. Cooper GS, Gilbert KM, Greidinger EL, et al. Recent advances and opportunities in research on lupus: environmental influences and mechanisms of disease. *Environ Health Perspect.* 2008; 116(6): 695–702. [PubMed: 18560522]
6. Powell JJ, Van de Water J, Gershwin ME. Evidence for the role of environmental agents in the initiation or progression of autoimmune conditions. *Environ Health Perspect.* 1999; 107(suppl 5): 667–672. [PubMed: 10970167]
7. Pugliatti M, Harbo HF, Holmoy T, et al. Environmental risk factors in multiple sclerosis. *Acta Neurol Scand Suppl.* 2008; 117(suppl s188):34–40. [PubMed: 18439219]
8. Schmidt S, Allen KD, Loiacono VT, et al. Genes and environmental exposures in veterans with amyotrophic lateral sclerosis: the GENEVA study. Rationale, study design and demographic characteristics. *Neuroepidemiology.* 2008; 30(3):191–204. [PubMed: 18421219]

9. Seaman V, Dearwent SM, Gable D, et al. A multidisciplinary investigation of a polycythemia vera cancer cluster of unknown origin. *Int J Environ Res Public Health*. 2010; 7(3):1139–1152. [PubMed: 20617023]
10. National Center for Environmental Health. Investigating suspected cancer clusters and responding to community concerns: guidelines from CDC and the Council of State and Territorial Epidemiologists. *MMWR Recomm Rep*. 2013; 62(RR-08):1–24.
11. Harada T, Ishida M. Neoplasms among A-bomb survivors in Hiroshima: first report of the Research Committee on Tumor Statistics, Hiroshima City Medical Association, Hiroshima, Japan. *J Natl Cancer Inst*. 1960; 25:1253–1264. [PubMed: 13711417]
12. Mabuchi K, Soda M. A review of forty-five years study of Hiroshima and Nagasaki atomic bomb survivors. Tumor registries and cancer incidence studies. *J Radiat Res (Tokyo)*. 1991; 32(suppl): 239–244. [PubMed: 1762111]
13. Sánchez-Porro Valadés P, Posada de la Paz M, de Andrés Copa P, Gimenez Riboto O, Abaitua Borda I. Toxic oil syndrome: survival in the whole cohort between 1981 and 1995. *J Clin Epidemiol*. 2003; 56(7):701–708. [PubMed: 12921940]
14. Nwomeh BC, Lowell W, Kable R, Haley K, Ameh EA. History and development of trauma registry: lessons from developed to developing countries. *World J Emerg Surg*. 2006; 1:32. [PubMed: 17076896]
15. Burg JR, Gist GL. The National Exposure Registry: procedures for establishing a registry of persons environmentally exposed to hazardous substances. *Toxicol Ind Health*. 1995; 11(2):231–248. [PubMed: 7491637]
16. Schultz MG, Sapp JH, Cusack CD, Fink JM. The National Exposure Registry: history and lessons learned. *J Environ Health*. 2010; 72(7):20–25. [PubMed: 20235405]
17. Antao VC, Larson TC, Horton DK. Libby vermiculite exposure and risk of developing asbestos-related lung and pleural diseases. *Curr Opin Pulm Med*. 2012; 18(2):161–167. [PubMed: 22139761]
18. Farfel M, DiGrande L, Brackbill R, et al. An overview of 9/11 experiences and respiratory and mental health conditions among World Trade Center Health Registry enrollees. *J Urban Health*. 2008; 85(6):880–909. [PubMed: 18785012]
19. Antao VC, Pallos LL, Shim YK, et al. Respiratory protective equipment, mask use, and respiratory outcomes among World Trade Center rescue and recovery workers. *Am J Ind Med*. 2011; 54(12): 897–905. [PubMed: 21932428]
20. Antao VC, Horton DK. The National Amyotrophic Lateral Sclerosis (ALS) Registry. *J Environ Health*. 2012; 75(1):28–30. [PubMed: 22866401]
21. Mehta P, Antao V, Kaye W, et al. Prevalence of amyotrophic lateral sclerosis—United States, 2010–2011. *MMWR Surveill Summ*. 2014; 63(suppl 7):1–14.
22. Goldhaber MK, Tokuhata GK, Digon E, et al. The Three Mile Island Population Registry. *Public Health Rep*. 1983; 98(6):603–609. [PubMed: 6419276]
23. Mallonee S, Shariat S, Stennies G, Waxweiler R, Hogan D, Jordan F. Physical injuries and fatalities resulting from the Oklahoma City bombing. *JAMA*. 1996; 276(5):382–387. [PubMed: 8683816]
24. Lomat L, Galburt G, Quastel MR, Polyakov S, Okeanov A, Rozin S. Incidence of childhood disease in Belarus associated with the Chernobyl accident. *Environ Health Perspect*. 1997; 105(suppl 6):1529–1532. [PubMed: 9467077]
25. Pitkevitch VA, Ivanov VK, Tsyb AF, Maksyoutov MA, Matiash VA, Shchukina NV. Exposure levels for persons involved in recovery operations after the Chernobyl accident. Statistical analysis based on the data of the Russian National Medical and Dosimetric Registry (RNMDR). *Radiat Environ Biophys*. 1997; 36(3):149–160. [PubMed: 9402631]
26. van Kamp I, van der Velden PG, Stellato RK, et al. Physical and mental health shortly after a disaster: first results from the Enschede firework disaster study. *Eur J Public Health*. 2006; 16(3): 252–259.
27. Thomas AR, Marcus M, Zhang RH, et al. Breast-feeding among women exposed to polybrominated biphenyls in Michigan. *Environ Health Perspect*. 2001; 109(11):1133–1137. [PubMed: 11712998]

Factors to Consider Before Establishing an Environmental Health Registry

Is a Registry Acceptable?	Is a Registry Feasible?
Public health significance of event or outcome	Ability to address exposure/health concerns of population
Scientific significance of registry	Reasonable timeliness
Well-defined purpose	Sufficient funding
Clear outcomes from registry	Appropriate staffing
Well justified duration and scope of data collection	Adequate communications capabilities with registrants
No alternative data sources	Ability to collect the necessary information

TABLE 1
Examples of Environmental Health Registries Conducted by the Agency for Toxic Substances and Disease Registry

Registry	Target Population	Period of Operation	Enrollees, No.	Data Sources	Estimated Implementation Costs, \$
National Exposure Registry	People exposed to hazardous substances in residential areas (trichloroethylene, benzene, 1,1,1-trichloroethane, Dioxin)	1989–2000	8 216	Interviewer-assisted self-reported surveys; a portion of health data was verified with medical records	6 million
Tremolite Asbestos Registry	Persons exposed to Libby vermiculite	2003–present	9 110	Self-reported surveys	3 million
World Trade Center Health Registry	Rescue and recovery workers, lower Manhattan residents; lower Manhattan office workers; passersby on September 11, 2001; students and staff in lower Manhattan schools	Wave 1: 2003–2004 Wave 2: 2006–2008 Wave 3: 2011–2012	71 434 46 602 43 134	Self-reported surveys	23.5 million
National Amyotrophic Lateral Sclerosis Registry	People with amyotrophic lateral sclerosis	October 2010–present January 2001–present	NA ^a	Self-reported surveys (Web portal), administrative databases (Medicare, Medicaid, Veterans Health Administration, Veterans Benefits Administration), and National Death Index	12 million

Note. NA = not applicable.

^aCurrently, number of enrollees cannot be disclosed, per Office of Management and Budget terms of clearance.

TABLE 2

How Environmental Health Registry Criteria Have Been Applied in Actual Situations

Criteria	World Trade Center Health Registry	National Amyotrophic Lateral Sclerosis (ALS) Registry	Chlorine Release at a Poultry Processing Plant in Arkansas (600 workers exposed, 170 hospitalized)
Is a registry warranted?	Yes	Yes	No
Public health significance	Unprecedented terrorist mass casualty event with uncertain public health impact	Progressive and fatal neuromuscular disease No cure has been identified No national estimates on incidence or prevalence	Single plant exposure, no fatalities
Scientific significance	Exposure to a mixture of many noxious substances and horrific events	Information on risk factors may provide clues to etiology	Health effects of chlorine exposure are well known
Well-defined purpose	Follow health outcomes of exposed population	Collect demographics and risk factor information	Uncertain; potential to analyze risk factors for prolonged health effects
Clear outcomes	Generate data for research	Generating data for research Improve the delivery of health services	No particular reason to follow workers over time
Well-justified scope	Exposed population restricted to lower Manhattan	National scope	No registry warranted
No alternative data sources	Alternative data sources were restricted to specific groups, such as firefighters.	Not a reportable disease Medical records are difficult to obtain on a national basis	Personnel and medical records readily available
Is a registry feasible?	Yes	Yes	No
Ability to address concerns	Sufficient sample size and well-defined exposure	Administrative databases provide more than 80% of cases Close relationship with patient support organizations and scientific community	Potentially could help reassure workers about long-term health effects
Reasonable timeliness	Registry effort started in July 2002, 10 mo after event; data collection began in September 2003	Launched 1 y after congressional mandate	Uncertain how long would it take to establish a registry If plant was supportive, could be done quickly
Sufficient funding	\$23.5 million of initial funding	\$12 million of initial funding	No funding for a registry
Appropriate staffing	Collaborative effort between ATSDR and the New York City Department of Health and Mental Hygiene, which has staff dedicated exclusively to the registry	Medical epidemiologists, statisticians, and IT contractors dedicated to registry maintenance	No additional staff available
Communication capabilities	A contractor was charged with promoting registry and conducting outreach	Partnership with patient support organizations and medical societies Extensive social media outreach	Language barriers (most workers were Spanish- or Marshallese-speaking)
Ability to collect information	Telephone, in-person, and Web-based interviews	Use of administrative databases and self-registration web portal	Would require translation of questionnaires into Spanish and Marshallese and interview staff fluent in these languages

Note. ATSDR = Agency for Toxic Substances and Disease Registry.